

BEST PRACTICES:

Windsor-Essex Model for Adult Developmental Services
Locally Designed • Community-Developed • Conducive to Government Policy

Family Perspective
Windsor-Essex Family Network

August 16, 2004

*Parents from Windsor-Essex Family Network
present the family perspective . . .*

BEST PRACTICES:

Windsor-Essex Model for Adult Developmental Services

Locally Designed • Community-Developed • Conducive to Government Policy

BACKGROUND

In 1997 the Windsor-Essex Restructuring/Community Planning Committee for Adult Developmental Services took the Ministry of Community and Social Services (MCSS) policy document 'Making Services Work for People' (MSWFP) to heart. Participants from the community wanted to ensure that supports and services would work for people who had a developmental disability and their families. Community Planning Committee members worked tirelessly to design a system that would be practical and meaningful for people's lives, result in efficient use of resources, provide help to those most in need and offer a fair way to allocate resources. Their work of four years went beyond expectations. Key features were put in place that went further than what the MSWFP document had outlined with a passion to truly empower people and families. In the end, the eight volunteer consumers, (four family members, four self-advocates), and eight agency representatives succeeded in creating a model our community can be proud of. The Southwest Regional Office of MCSS supported the direction.

The Windsor-Essex County model had great potential to ensure that people with developmental disabilities would be empowered to express what they wanted, have real choices, and design their individualized supports with the help of their families and friends . . . all of this, instead of having to fit into what already existed.

Limited resources in the last few years have made it difficult for all who need help to be supported. In addition MCSS modified the original model somewhat to fall in line with the wishes of the government of the day. Those who have been able to utilize designated funding and the features of the newly restructured system have seen their lives improved. Families have looked at their adult sons and daughters, or brothers and sisters, in a new light. Lives have definitely changed and stories are starting to be told. Many are achieving or working on their 'good-life' in the community. We are optimistic about the future.

TODAY IN 2004:

KEYS THAT POINT TO SUCCESS IN WINDSOR-ESSEX

1.

Having a Say - Making Real Choices:

A Key Role for the Focus Person (with the help of family, friends & others)

“Listening deeply to that often ‘silenced-voice’ has been difficult as people with disabilities have not traditionally had a say in directing their lives. Listening does not come naturally to the rest of us.”

Windsor-Essex Community Planning Committee participants were driven by their strong commitment to listen and respond to what people who have a developmental disability say they want. This group embraced the term **person-directed planning** at the request of People First members and self-advocates early into the MSWFP restructuring process. As such, it has become our community’s ‘mantra’ and our reminder to always listen to the person who has been labelled. Person directed-planning means the person can communicate in their own way as to where he or she wants to live, what he or she wants to do each day, who he or she would like to live with and who would provide support. The person is the ‘director’. We truly believe in the People First principle that says “nothing about me without me”.

A commitment was made (as a community) to empower people with disabilities, with the help of their family and friends, so they could direct their own lives to the degree they are able. *We believe that, with support, people can dream, plan, make choices and have control over their own destiny, including changing their path as needed. It is our responsibility to listen and help make this happen for our family members.* This is not an easy task. We all must be reminded of the importance of this and keep working at it – families, friends, and paid supporters.

Many individuals and families continue to communicate loud and clear that they want to have a say in decisions regarding their futures. Individuals, along with their families, have told us they like having choices and the ability to tailor their supports to enable participation in their community just like any other citizen of this province.

2.

Independent Planning Support

A Key Role for Windsor-Essex Brokerage for Personal Supports

“I have someone helping me who works just for me”

As families, we believe that independent planning support is the best option for people to be heard and empowered. We are glad that this option is available in our community. It was formally put in place as a result of the MSWFP restructuring process. **Independent unencumbered planning and facilitation** is available through Windsor-Essex Brokerage for Personal Supports (WEBPS), our central point of access for information. We have heard families talk about how helpful this organization has been to their son or daughter and/or sister or brother. WEBPS, (also nicknamed ‘brokerage’) has modelled the importance of listening deeply to what the focus person is communicating – verbally and non-verbally.

In addition, other services offered by ‘brokerage’ have been much appreciated by individuals and families. These include:

- up-to-date information on all available community options so that informed decisions can be made;
- shopping for supports and services;
- mediation and/or negotiation of funding and supports;
- planning assistance to move dollar/supports when a change is desired;
- assistance with the writing of contracts;
- facilitation at planning meetings where different outcomes exist between the focus person and their parents, or the family and service providers;
- researching information for those who pioneered new, inclusive community solutions for their family member thus creating positive examples for change within the service system.

Families have told us that lives have also improved for their family member who already had existing supports because they were able to negotiate a different support package with the help of ‘brokerage’. Others report creating something completely unique in the community — this as a result of an allocation of support dollars and being able to handpick their team of support workers. In addition, working with service providers to implement what is outlined in their personal support agreements (contracts) has also been positive for a number of people – again often as a result of involvement with ‘brokerage’.

We believe that planning for a full life in community works best when:

- the person who assists with planning works **ONLY** for the focus person;
- trial and error is a natural part of the ongoing process of planning;

- the focus person's supports are able to evolve flexibly as life changes;
- portability of funding is an option;
- the accountability and monitoring responsibilities are laid out in a personal support agreement that is written with the help of a third party facilitator

3.

Financial Accountability, Monitoring & Human Resource Support A Key Role for MCSS Funded Transfer Payment Agencies

Service providers currently play a key role with regard to accountability and monitoring in the partnership with individuals and families. They have the responsibility of ensuring quality of life through monitoring. They also carry out the financial accounting and may assist with human resource issues as needed.

Agencies also have a role to play in offering quality supports and services to those who are purchasing their services. Families play a role also. They are as involved as they choose: from self-administering their own arrangements, to receiving recruitment/hiring support, or requesting an agency to provide all the supports.

Agencies in Windsor and Essex County have tried to be creative and helpful with those people who have designated dollars that are wanting more creative options. Implementation approaches have been designed and are being tested. There are some real success stories. However, families do reflect that creativity can be difficult within the existing system. Some families have expressed the need for an infrastructure support that could assist more flexibly.

4.

Prioritizing Requests for Support A Key Role for the Community

We are pleased with the decision by our MCSS Regional Office to support and maintain the current Priority Process. It was designed to be a respectful, anonymous process that values 1) people's privacy and 2) fairness above all else. It operates through a coordinated access model in the community with the support of a '*process coordinator*'. After talking with families around the province, we truly believe this process has the potential to be the most respectful and effective process in Ontario. We also believe, however, that returning to the original intent of having a steering/advisory committee to oversee the process and support the efforts of the panel and coordinator would better secure this process into the future.

We are proud of the families and individuals who worked hard expressing the importance of this design at the Community Planning 'table'. They worked with other participants to ensure that individual privacy was valued not only through an anonymous process, but through the use of a panel of our peers from the community. This process was modelled after one in Western Australia and was also recommended in a consultant's report during the MSWFP restructuring days. (The report entitled, '*System Review of Adult Developmental Supports and Services, Windsor-Essex County, 1999*', was authored by consultant Don Gallant.)

Breaking with tradition in Ontario where executive directors and other service providers consider requests for support and know individual names and situations was an adjustment for some in our community. We know it has been difficult.

We are grateful to the wonderful volunteers on the Priority Panel who currently give of their time to review requests for support. They have had the fortitude to learn about the many, many extremely desperate situations in our community - a heart wrenching and difficult task.

5.

Allocation of Funding, Accountability Standards **A Key Role for the Government**

MCSS determines the amount of funding available provincially, decides upon what target areas the funding will be spent and how much funding will be designated to each region in the province. Local allocation decisions are made once the prioritization process is complete.

There are individuals and families in Windsor and Essex County, deemed 'most in need' since 1999, who have been allocated designated dollars for supports. They have then chosen which transfer payment agency would receive the designated funds on their behalf.* They have also decided what services will be purchased and how they will be assisted with the accountability and quality standards of the government. **Being able to let the government know which service provider will be accountable for the designated dollars is empowering and respectful.*

As families, we believe it is important to **continue** having dollars designated for people's support needs:

- 1) through a fair, anonymous and objective process;
- 2) for the design and/or purchase of their individualized supports;
- 3) to ensure flexibility;
- 4) with the option of portable funding if things changed in the future.

HOPES FOR THE FUTURE

The current system in Windsor and Essex County offers some **exceptional** options for individuals and families. However, we believe that the following enhancements would: improve the system, empower people further and increase the quality of life for many more people and families. We hope that the Ministry of Community and Social Services will consider:

1) An expansion of independent planning and facilitation.

This speaks for itself. When planning support is not vested in direct service delivery the person's needs are front and centre. Personal Support Agreements are most effective when an independent facilitator assists with writing the agreement.

2) Securing the current 'priority panel' process into the future.

The establishment of a steering and/or advisory committee of volunteers who value the model would ensure community input, direction and support.

3) Financial resources to meet the dire needs in the community.

Adequate funding and planning support for the 250 plus adults (and their families) on the priority list, many of whom feel in crisis, would go a long way. Also in need are those families who have not applied for supports, aware that there are no dollars available.

4) Establishment of an independent structure to support creative and individualized options.

The support that some families describe would be helpful, in addition to 'brokerage', is an independent option for carrying out the financial accountability, and/or payroll and/or help with human resource issues. Such an option would not be compromised by existing direct service delivery programs, traditional systems and/or arrangements that have developed out of another day and time. An independent structure would have more ability to offer the flexibility needed to support the creative ideas people have been designing and choosing. (In Manitoba, payroll support has been provided by local banking institutions for those who have individualized funds.) The concept for this type of financial and human resource supports was initially recognized as a gap in Windsor-Essex in 1996. Plans for a 'payroll co-op' were underway through the late 90's but it never came to pass. The need has become even more apparent and the gaps more clearly identified as more individualized supports are creatively being developed over time. People and their families have had to work very hard at times to make their dreams come true without this support.

SUMMARY

Despite some of the drawbacks, the key features in the Windsor-Essex County model have enabled people with developmental disabilities and their families to choose the support they want -- whether it is traditional service, a unique and individualized creation or a combination of both. We have seen the Windsor-Essex model work for individuals living with senior parents, younger working parents, people who are transitioning from high school, people wanting to live on their own and folks with significant and complex health issues. This has made it a win-win. We have also seen things change and evolve for people as they grow; are empowered; gain skills; or develop new interests. They have then been able to make changes to their supports.

We know that...

- **People must be listened to ‘deeply’.** They often know what they want and need but may require assistance and time to learn to express it. Being listened to leads to a desired quality of life. Unencumbered planning that is person-directed -- really works.
- **Flexible and portable supports empower people and demonstrate respect.** People’s lives constantly change; therefore, they need to be able to change their supports.
- **Support that is dependable, secure and adequate works best.** Disability is life long, therefore, people and families need to be able to count on support at each stage of life.
- **Non-traditional supports and opportunities have led to change, offered value and made improvements to people’s quality of life.** This has been demonstrated by current research and experience. Examples include: Western Australia, Options (in Toronto), the Windsor-Essex experience.
- **Independent infrastructures work.** They balance the pull of traditional systems and ensure change for the people (and their support networks) who want to design, create and/or live out a unique individualized support situation in the community.

With continued support from the Regional Office of the Ministry of Community and Social Services for this “made in Windsor-Essex model” we look forward to doing whatever it takes to ensure a good life for our loved ones. As families, we hope to do this in the manner each of our adult children would want and need to **‘be strong and well supported.’**